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When Good Intentions Backfire: University Research Ethics Review and the Intimate Lives of People Labeled with Intellectual Disabilities

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Key words: intellectual disability; disablism; qualitative research; ethics; ethics review; research regulation; vulnerability; intersectionality; student research

Abstract: We critically discuss how practices of ethical governance through university research ethics committees can contribute to the silencing of people labeled with intellectual disabilities through the reproduction of discourses of vulnerability and protectionism. In addition, disabling assumptions of (in)ability and reductive bio-medical understandings of labeled people as a homogeneous group can create concern that such research is "too risky," and perhaps not valuable enough to outweigh potential risks. Combined, these practices deem people "too vulnerable" or "too naïve," and thus, unable to make decisions for themselves about participating in research without putting themselves and the researcher(s) at risk. In this article, we draw on insights gained from our experiences undergoing ethics review for projects focused on the personal and intimate lives of people with intellectual disabilities. We proffer that such ethical governance, though well-intentioned (i.e., to protect participants and researchers), limits not only possibilities for research that would otherwise prioritize the perspectives and agency of people with intellectual disabilities but also how researchers are "allowed" to engage with them in research.

Table of Contents

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1. Introduction

The protection and ethical inclusion of people labeled with intellectual disabilities[1] in research is a serious matter, especially considering long-standing precedents of unethical research (IACONO, 2006; McDONALD, KIDNEY & PATKA, 2012) that have significantly harmed and exploited disabled people, practices that reflect their long history of experiencing abuse, discrimination and exploitation in all aspects of their daily lives (FUDGE SCHORMANS & SOBSEY, 2007; LIDDIARD, 2011). At the same time, it is also unethical to assume that people labeled with intellectual disabilities cannot make their own decisions and, though greater care may be needed, people with intellectual disabilities have the right to share their perspectives and "speak" on their own behalf—in their daily lives as well as through their active inclusion in research. [1]

One area in which people labeled with intellectual disabilities (henceforth, labeled or disabled people) have historically been afforded few opportunities to communicate their experiences and desires concerns their personal and intimate lives, including their friendships, parenting, family relationships, or romantic and sexual experiences. In comparison with their non-disabled peers, these are typically spoken for them by other social actors in their lives (e.g., parents, support workers, professionals) (KELLY, CROWLEY & HAMILTON, 2009). The United Nations' Convention on the Rights of People with Disabilities recognizes the equal and inalienable rights of people with disabilities to personal and intimate relations and marriage, as well as freedom of choice and self-determination in various aspects of life (STOFFELEN, SCHAAFSMA, KOK & CURFS, 2018). McDONALD and KEYS (2008) note that due to impairment not all people with intellectual disabilities are able to make significant decisions in their lives, though this is a small percentage. We know, too, that for many others the "ability" to make decisions and speak for oneself have been compromised as a result of assumptions around (in)ability leading, for example, to a lack of education, opportunity and supports (such as communication aides) to do so (FUDGE SCHORMANS, KRAUSE, MacDOUGALL & WATTIE, 2011). These and other *disabling* structural and attitudinal barriers often prevent them from participating in research and sharing their own perspectives.[2] [2]

1 Keeping in mind that terminology varies greatly across regional contexts and disability circles (GILL, 2015), we use the terms "labeled people" and "disabled people" as well as "people with intellectual disabilities" interchangeably as an attempt to respect the varied perspectives among disabled scholars and activists. People first language, as exemplified by the term "people with intellectual disabilities," is preferred by some groups of self-advocates with intellectual disabilities. The more political terms "labeled people" and "disabled people", which are prevalent among North American scholars/activists working from a critical disability lens (IGNAGNI, FUDGE SCHORMANS, LIDDIARD & RUNSWICK-COLE, 2016), "acknowledges that the label of disability has been applied by another person and is not always owned by the individual with regard to whom it is used" (MCCLELLAND et al., 2012, p.809).

2 In contrast with a biomedical understanding of disability, which conceptualizes disability as a "medical problem" residing in people with disabilities necessitating cure or care by medical/professional experts, disability studies scholars have turned our attention to how people with disabilities are *disabled* by structural, social and environmental barriers (SHAKESPEARE, 2014; THOMAS, 2002).

In this article, we critically discuss how practices of ethical governance through university research ethics committees can contribute to the silencing of labeled people through the reproduction of discourses of vulnerability and protectionism. In addition, disabling assumptions of (in)ability and reductive understandings of labeled people as a homogeneous group can create concern that such research is "too risky"—for both participants and the research itself—and thus perhaps not valuable enough to outweigh potential risks (i.e., "they cannot provide good data"). We acknowledge that there are always potential risks to participants, that those risks need to be explained to participants in clear accessible language, and that the well-being of research participants is extremely important; however, we have also witnessed how harm and risks can be overstated by ethics review committees (VAN DEN HOONAARD, 2002; VAN DEN HOONAARD & HAMILTON, 2016), especially when it comes to research involving people labeled with intellectual disabilities (McDONALD, SCHWARTZ, GIBBONS & OLICK, 2015). Combined, these practices deem labeled people "too vulnerable" or "too naïve" and thus unable to make decisions for themselves about participating in research without putting themselves, the research and the researcher at risk. Our research is located in Canada where the Tri-Council Policy Guidelines require all projects involving human subjects be approved by research ethics committees (VAN DEN HOONAARD, 2002; VON UNGER, DILGER & SCHÖNHUTH, 2016). In this article, we draw on insights gained from our experiences undergoing ethics review at a number of different Canadian universities for projects focused on the personal and intimate lives of labeled people. We draw on PLUMMER's (2003) work on "intimate citizenship" to think about the ways in which some types of ethical governance may impede labeled people's opportunities to be active participants in the production of knowledge about their lives. We argue that such ethical discipline not only limits possibilities for research that would otherwise prioritize the perspectives and agency of labeled people, but also how researchers are allowed to engage with labeled people in research. [3]

2. Nothing About Us Without Us

Historically, people identified with intellectual disabilities have been seen as not being "competent" enough to participate in research (LAI, ELLIOTT & OUELLETTE-KUNTZ, 2006) and, consequently, non-disabled people have been at the forefront of knowledge production (BOXALL & RALPH, 2009). However, there has been a greater emphasis on the importance of including labeled people in research about "intellectual disability" and the lives of people so labeled (McDONALD et al., 2015). It has been argued that this change "can spur new thinking about vulnerability and inclusion, and resonate with increasing attention to human rights" (p.205). The disability rights movement has long pushed for "nothing about us, without us" (CHARLTON, 1998), and research participants with intellectual disabilities and self-advocates have indicated the importance of speaking for themselves (FUDGE SCHORMANS et al., 2011; McDONALD et al., 2015). Previous studies have noted that participating in research can be a positive experience for people with intellectual disabilities who appreciate having an opportunity to have their voices heard, especially in hopes that their narratives can help make a difference in the lives of other labeled people (BIGBY &

FRAWLEY, 2010; FRANKENA et al., in press; FUDGE SCHORMANS, 2015). It is also important to people with intellectual disabilities to feel valued and included, and to have the opportunity to contribute to knowledge construction (McDONALD, CONROY, OLICK & THE PROJECT ETHICS EXPERT PANEL, 2016). Increasingly, the emphasis has been on collaborative research methodologies in which teams of researchers with and without disabilities work together in a range of ways that recognize and value the different contributions that each member of the collaboration makes (BIGBY & FRAWLEY, 2010; GUSTAFSON & BRUNGER, 2014; NIND, 2008). Collaborations with community members with intellectual disabilities also provide a different set of perspectives and experiences that can begin to change the opinions of the general community (FUDGE SCHORMANS, 2015; McDONALD et al., 2016). [4]

We both have worked extensively with people labeled with intellectual disabilities and self-advocates on various research and community initiatives that have allowed us to build ongoing relationships. We have also worked with different organizations serving people with intellectual disabilities and their families to help facilitate conversations about intimate citizenship. We both are committed to working collaboratively with people with intellectual disabilities in research, and in thinking critically about how such collaborations work. However, we still know very little about the attitudes of committee members of ethical review boards when it comes to studies involving labeled people. From our experience and that of others however, it is reasonable to say that their attitudes and awareness can facilitate or constrain research with vulnerable groups (LAI et al., 2006). Whereas we do not know how many ethics protocols involving people identified with intellectual disabilities are in fact approved or rejected (LAI et al., 2006), studies have consistently noted how receiving approval for research involving labeled people can be extremely challenging (IACONO, 2006). The significant barriers for researchers seeking ethics approval have discouraged some from speaking to labeled people themselves and sometimes led researchers to focus their research on the experiences of other social actors, such as family members and staff persons instead (McDONALD et al., 2015). It is worth noting that while we are currently at the same university, our experiences cross more than one university and more than one province suggesting that this is not a local phenomenon and that our experiences might speak to those of other disability scholars. [5]

3. Medical Approach to Disability

One of the most significant concerns we have is that the decision-making of members of ethics committees appears firmly rooted in reductive medicalized understandings of disability (see, also, MORGAN, CUSKELLY & MONI, 2014). For a long time, the medical model has conceptualized disability as a "medical problem" that resides in disabled people and must be "fixed" or "eradicated," has equated disabilities with "flawed" minds and bodies, and constructed disabled people as "victims" of impairments (GOODLEY, 2010; SHAKESPEARE & WATSON, 2001). The field of critical disability studies has done the radical work of shifting our attention from understandings of disability based on medical,

charity, and individualized approaches to a more structural one (BECKETT, 2006; SHAKESPEARE, 2014). Key to this reconceptualization is the construct of *disablism*. Disablism is understood as "a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities" (CAMPBELL, 2009, p.4) and ableism as "a network of beliefs, processes and practices that produces a particular kind of self and body ... that is projected as the perfect, species-typical and therefore essential and fully human" (CAMPBELL, 2001, p.44). This privileging of a "corporeal standard" is why medical models prevail and why disability then is cast as a "diminished state of being human" (p.44). It is important to acknowledge how "disablism and ableism (and disability and ability) can only ever be understood simultaneously in relation to one another" (GOODLEY, 2010, p.xiii). [6]

We understand that each ethics review committee is likely to have different internal dynamics and to be always in flux. Nonetheless, our experiences, as well as those of other scholars in the field (see for example, LAI et al., 2006), with ethics review committees in different Canadian universities and at different times suggest a consistent response when it comes to projects involving people labeled with intellectual disabilities. In our own experiences, we have consistently received feedback that clearly followed a medical approach to disability. For example, both of us have been asked (and even told) to rely on I.Q. measures to make decisions about who should and should not participate in the research. In response, we have spent a significant amount of time educating ethics review board members about the various approaches to understanding disability and about disablism, approaches that do not rely on medical standards like I.Q. measures. Sometimes this has been sufficient. At other times, we have "agreed" (albeit reluctantly) to recruit participants through disability service organizations and self-advocacy groups, in which case the "diagnosis" of intellectual disabilities has already been made. In another instance, one of us was asked during a meeting with an ethics committee member about whether they were interested in interviewing people with "mild disabilities" or "those really retarded ones." This was said while the speaker gestured with their hands to indicate this apparent hierarchy, waving their hand at the level of the top of their head to indicate "mild disabilities" and at the level of the table to indicate the latter. Taken aback by this utterance, the researcher said nothing in reply. [7]

Questions regarding the "severity" of impairment have been common, most often accompanied by "requests" or even the "requirement" that we do not include as participants labeled persons "diagnosed" with anything other than "mild" impairment. The notion of (in)competence is plainly visible here. Whereas the use of medical evaluation and "standardized criteria" were highly encouraged and seen as more "objective" for making decisions about participants' ability to participate in research, our "impressions," based on knowledge of and interactions with people with intellectual disabilities, were considered to be "confirmatory but ... not definite." In one case, one of us felt there was little choice but to agree to the request to use "tell-back questions" as a way to make sure that participants understood the study, including its potential benefits and risks,

and were able to make informed decisions regarding their participation in the study. This approach disregards how diagnostic labels along with standardized tests ignore the heterogeneity among labeled people and are partial. In addition, some participants reported that having to answer "tell-back questions" was tedious and unnecessary. This bio-medical approach is perhaps not surprising considering how ethics review boards have traditionally followed standards grounded in bio-medical sciences (VAN DEN HOONAARD, 2001; VON UNGER et al., 2016), as seen, for example, in the language of documents used by research ethics committees (MILNE, 2005). [8]

Requiring researchers to seek out and rely upon diagnostic categories and evaluations in determining who can and cannot participate in research reinforces the notion that medicalized models have more legitimacy in comparison with other approaches to understanding disabilities (for example, a social model or critical disability studies approach). Incidents such as the one in which the ethics committee member referenced degree of "retardation" of potential participants demonstrate the apparent ignorance, the lack of current knowledge about intellectual disability and people so labeled amongst at least some members of ethics committees. The use of what the intellectual disability community terms "the R-word" has been actively discouraged for many years in Canada and elsewhere, not only in cultural and service-based spheres, but also at the level of governments (LYLE & SIMPLICAN, 2015). Use of such language by ethics committee members may reflect ignorance of alternative understandings and shifts in understandings of disability, or it may be an indication of disablism (CAMPBELL, 2009). This lead us to wonder how the adoption of a more critical and emancipatory approach to disability might work to re-shape ethics procedures and decisions. [9]

What is also of importance is the question of whose job it is to educate members of ethics review boards. We understand from our own conversations with members of ethics committees that serving as an ethics committee member is typically voluntary labor conducted in addition to one's regular responsibilities; and that it can be difficult to keep updated. Yet, it would seem reasonable to expect that when someone chooses to become a committee member, they have accepted some responsibility to learn. Such learning, however, must also be supported by the university: time and space for learning must be provided. Additionally, we believe that there is a need to have a more diverse committee membership that can better address different types of research methods and projects. As ethics review committees hold such high standards and scrutinize projects involving labeled people to such an extent, we wonder whether researchers should also be able to hold the ethics committee—and, by extension, the university—to the same standards. It is noteworthy how we both hoped that our multiple meetings with and extensive written responses to ethics committees would have resulted in some learning. And, in one instance, one of us has seen such a shift occur (although it proved to be short lived). Whereas it is certainly arguable that membership on ethics committees changes regularly, thus impacting such a proposition, very shortly after one of us had a recent and lengthy engagement with a particular ethics committee about a project exploring sexuality and

intellectual disability, another student proposing a project about intimacy (in this case, friendships) faced similar challenges from the same board. [10]

There is an urgent need for ethics review committee members to catch up when it comes to research involving people labeled with intellectual disabilities. It appears to be a reasonable request that committee members: educate themselves on 1. changes in scholarly and cultural understandings of "intellectual disability," 2. the "abilities" of people so labeled, 3. language that is preferred by members of disability communities, 4. critiques of reductive medicalized perspectives that pathologize and disable labeled people, 5. useful supports to facilitate research participation, 6. important shifts in attitudes, and 7. rights (and demands) to participation and empowerment (GUSTAFSON & BRUNGER, 2014). [11]

4. Focus on Risk and Vulnerability

Previous studies have suggested that university ethical governance leans towards conservatism, including a tight over-regulation with the aim of avoiding potential harm, which leads to barriers to labeled people's participation in research (BOXALL & RALPH, 2009; IACONO, 2006). There is, for example, a shared fear among researchers in terms of making amendments to their ethical protocols due to a fear that an "ensuing amendment may become mired down or even lead to additional stipulations to the existing protocol" (AMAN & HANDEN, 2006, p.181). More so, as we experienced, the ethics review process may take a long time for projects involving labeled people, thus sometimes putting research on hold for a significant amount of time. At other times, such as for students in time limited programs, this can threaten if not completely sabotage a project altogether (PEARCE, 2002). Students often occupy a more "vulnerable [position] and are usually not well placed in the social organization of research to resist ethical norming" (VAN DEN HOONAARD, 2002, p.5). One of us has struggled with the tension created by the need to support students to successfully complete the ethics process in time to conduct and complete their research project, while worrying that "doing what is demanded" will become a dangerous precedent. This can withhold potential improvements in conducting research and may, in fact, set research with labeled people back even further. [12]

The assessment of risks and benefits behind research projects has become one of the major tasks of ethics review committees (MILNE, 2005). The problem, however, is that often "well-intentioned but onerous regulations are justified on the basis of hypothetical worst-case scenarios and then normalized across a vast range of research" (HAGGERTY, 2004, p.403). For people labeled with intellectual disabilities, all of the above tends to be rooted in questions of competence and vulnerability, and the risks believed to accrue from such. There is such a focus on questions of vulnerability and risk that, not surprisingly, in their early studies as a master's student, one researcher experienced significant "ethnographobia" (JACKSON, as cited in BLEE & CURRIER, 2011, p.404), finding themselves blocked by the fear of potentially causing any form of emotional harm to their participants, despite their previous experiences working closely with labeled people. Both researchers have been encouraged by

members of different ethics committees, at different times, to refrain from interviewing labeled people and instead focus on parents or workers supporting labeled people. The understanding was that such projects would avoid "complex" and "complicated" ethical questions. In our own experiences, we have many times had to insist on the importance of including labeled people in research, both through written responses and multiple meetings with the ethics committees. [13]

In addition to challenges posed by ethics review boards, access to people with intellectual disabilities to participate in research can involve going through a series of gatekeepers, informing them about the research, building rapport, and discussing the importance and benefits of the research (LENNOX et al., 2005; NIND, 2008). Depending on guardianship arrangements, family members or other legal guardians may need to provide consent along with the participant's assent (LENNOX et al., 2005). Even where there are not guardianship orders, it is worth noting how that gatekeeping often applies to labeled adults and not just children with intellectual disabilities, due to the infantilization of labeled people. As researchers, we are often constrained, if not forced, to take on particular language around disability and follow these infantilizing procedures that disempower research participants. The medicalized understandings of disability often taken by gatekeepers and ethics review committees, the focus on harm, risk and vulnerability, along with the common infantilization of people with intellectual disabilities, forces researchers to follow all these steps, to operate within a medicalized, pathologizing framework, because that may be the only way to be allowed to do this kind of research. Connected to this gatekeeping, there are many disabled people, particularly those under guardianship orders, we don't get to talk to. Our access to potential participants and co-researchers is often restricted to a small and narrow range; labeled people who can speak for themselves. The most important consequence being that there are a lot of people we know nothing about (BOXALL & RALPH, 2010). [14]

The medicalized approach to disability commonly adopted by ethics review boards undoubtedly shapes, and is shaped by, institutionalized understandings of vulnerability. As noted by GUSTAFSON and BRUNGER (2014), the notion of "vulnerability, although a socially constructed label, is biologically embedded or firmly attached to a physical, functional, or developmental difference" (p.1000). Dominant understandings of labeled people as being in need of protection or lacking the ability to make informed decisions about research involvement can sometimes limit who is deemed to be able to provide consent and lead to unnecessarily restrictive research practices (McDONALD & KEYS, 2008). BUTLER, GAMBETTI and SABSAY (2016) argue that the adjectival label "vulnerable" leads to and legitimates—indeed, makes necessary—protectionist interventions, irrespective of who that label is applied to. In the case of research with labeled people, ethics committee members, positioned as both gatekeeper and protector, are thus charged with the responsibility of protecting this vulnerable group, even if this means at times to silence them. [15]

Our experience with ethics review boards has also made us aware of another important question in terms of just who it is that is at risk—the participant or the

researcher or the university—in research involving labeled people. Responding to IACONO's (2006) work, AMAN and HANDEN succinctly note:

> "We all know that the primary mandate of IRBs is—first and foremost—to protect study participants. However, in this climate of fear coupled with extreme ‘‘administrative constipation", many investigators wondered aloud if the true hierarchy was protection of (a) self (the IRB), (b) the institution, (c) the participant, and (d) the investigator (in that order)" (2006, p.180). [16]

Indeed, our own experience demonstrates that there seems to be some ambiguity about who requires protection as labeled people are sometimes constructed both as being in need of protection *from* the researcher as well as being a potential danger *to* the researcher. Participants with intellectual disability have been constructed either as being vulnerable, and thus at risk of harm from the research, or as being "deviant," "uncontrollable," and thus representing a risk to the researcher at work. At multiple times in the ethics review process, we are reminded that people with disabilities are a vulnerable group and that extensive measures must to be put into place to protect them. For example, it has been suggested to both researchers and to more than one student supervised by one of the researchers that they have someone present in the interview who knows the participant well and can thus "intervene" if the research causes the participant too much stress: it was not considered sufficient to have support persons in another room should this occur. This not only speaks to a perceived need for protection for all labeled people and a general inability to manage more difficult topics, it also fails to attend to the ways in which the presence of others (e.g., support staff, family member, service agency representative) can work to silence people, or to impact the stories being told by labeled people in the interview context (PERRY, 2008). [17]

At the same time, we are asked to think about strategies to protect ourselves as researchers—and the university—from misunderstandings. Indeed, one of us was told to consider having a third-party present in all their interviews to protect themselves from "any distortions." In particular, this researcher was discouraged from one-on-one interviews if the participant was a woman in order to avoid "false accusations of sexual misconduct," thus creating a "vulnerable circumstance" for the researcher. Falling back on assumptions of (in)ability and (in)competence, the implication was that the label "intellectual disability" meant that anyone so labeled would misinterpret the interview interaction and thus pose potential problems to the researcher as well as potential liability for the university. At other times, one of the researchers has been cautioned that support persons should be present because the label of intellectual disability means participants are more likely to "lash out" or "become violent." [18]

There is a documented history of paternalism on the part of universities and research ethics committees towards disability communities (GUSTAFSON & BRUNGER, 2014). This paternalistic and protectionist attitude is partly rooted in the infantilization of people with intellectual disabilities—as a group—who are commonly seen as only and always "eternal" children: it is thus understood that

they will be unable to understand what research is and the topic under study; to have an opinion and a desire to share such (FUDGE SCHORMANS, 2015); or to make their own decisions, including that of whether or not to participate in research (NIND, 2008). This infantilization tends to lead to the constant questioning regarding the "competence" of people labeled with intellectual disability based on bio-medical understandings and measurement tools. Exclusion from research and denial of opportunities to share their experiences in their own words (or other ways) in comparison with other social actors in their lives is the result (ELDERTON, CLARKE, JONES & STACEY, 2014; KELLY et al., 2009). [19]

Both of us have experienced being asked, multiple times, about what people labeled with intellectual disabilities were supposedly "capable" of doing. This questioning of "capacity" is typically represented by the question, "Can they do that?" It has been made plain to us the assumption of ethics committee members is that "they can't." One of us was even asked whether there really was any benefit to interviewing labeled people as they supposedly "cannot provide good data." Other researchers have similarly reported being questioned about the "capacity" of people with disabilities, questioning reflecting bio-medical understandings of disabilities as well as discourses of vulnerability (see, for example, MELLO, 2016). Often this doubt as to labeled people's ability appears to stem from reductive and homogenizing assumptions—the idea that all people with a particular label are exactly the same. For example, a student of one of the authors, seeking ethics approval for an arts-based study on friendship amongst children with a particular label was told (paraphrasing) that having that particular "diagnosis" made such a project impossible. In this case, time played a significant factor in what happened next. Being in a 12-month program, there was not time available for the student and supervisor to mount a challenge that would support the proposed research and educate the board in the process. Significant compromises were required for the student to complete a research project: a different participant group, drawn not from the community but instead from a disability service provider, and having agency staff present during interviews about experiences and desires for friendship should participants become "upset" or "act out." Whereas ethics reviews typically provide useful guidelines and suggestions (and indeed, this student did receive other feedback that was valuable), an over-reliance on diagnostic labels, the failure to attend to other influences or to acknowledge the heterogeneity of people living with a particular label significantly disadvantages people labeled with intellectual disability in the context of their participation in research. [20]

As noted in the literature, and confirmed in our experiences with ethics committees, there is such a significant focus placed on questions of risk, harm, vulnerability and informed consent during the ethics review process that it overshadows other important discussions (McDONALD et al., 2015), for instance, about ways to collaborate with labeled people in ethical and reciprocal ways (see BIGBY & FRAWLEY, 2010; FRANKENA et al., in press; WOELDERS, ABMA, VISSER & SCHIPPER, 2015). [21]

5. Shaping Relationships with Participants

The bio-medical language used in ethics forms and documentation as well as "the description of human subjects [as subjects], seems to privilege research that establishes a distance between the researcher and the researched" (MILNE, 2005, §12). Both of us continue to experience challenges in terms of having previous relationships or being known to people who belong to communities of people with intellectual disabilities who might choose to be participants in research projects. This has been seen as a conflict of interest that must not only be accounted for but is regarded as a "threat" to participants, potentially leading to abuse of power and coercion. While we understand that coercion and relations of power are serious matters, and can happen in subtle and unintended ways, the separation between researcher-participant often enforced by ethics review committees in contexts where this separation is blurred, generates different questions in terms of coercion and power relations (MILNE, 2005). Also, because some communities, such as communities of people with intellectual disabilities, are typically small (even in large urban centers) it is not uncommon (and likely very common) that researchers actively engaged with these communities will know and be known to potential participants. It is also not always possible, especially for student researchers, to travel outside of these communities. [22]

This has been an ongoing issue for one of the researchers who has been instructed by ethics committees that they cannot include people they know in the research project, even if those people would choose to be part of it. Whereas well-intentioned, this approach denies the agency of labeled people; deems them "incompetent" to make informed choices regarding research participation; and assumes that all researchers will be coercive. Although our research relationships may end at the conclusion of a research project, our relationships with labeled people may continue through our ongoing collaborative community and activist work. We tend also to agree with McDONALD and KIDNEY (2012) that our relationships with labeled people can deepen researchers' "understanding of the lived experience of intellectual disability and foster their commitment to pursuing inclusive, relevant, and sensitive research" (p.37). [23]

There is also something to be said about how participants may perceive researchers and their university—even if unintended by researchers—as prioritizing medicalized understandings of disability, understanding labeled people to be "vulnerable," in need of protection, and incapable of making informed choices about research participation (GUSTAFSON & BRUNGER, 2014). This disjuncture puts researchers in a difficult position where they can be perceived as abiding by "institutionalized exclusionary practices" (p.999), which can affect their relationships with people with intellectual disabilities. It can put researchers in a position where we have to find ways to negotiate these different, and sometimes conflicting, expectations and commitments that can affect our relationships with people with intellectual disabilities, and our ongoing community and activist work with them. [24]

6. Lack of Intersectional Lens

We have also noticed a recurring reductionist assumption that labeled people are always and only their disability. Participants are reduced to their biology, and the complexity of their lived experiences and identities is erased. It is important to remember that disability status is but one part of a person and that the lives of people with disabilities are shaped by various social locations and experiences (McDONALD & KIDNEY, 2012). Intersectionality refers to the insight that, rather than being mutually exclusive, social categories are mutually constitutive, and reinforce each other, working together in producing complex social inequalities that shape individual and group experiences (CHOO & FERREE, 2010; COLLINS, 2015). By thinking about intimate citizenship and intersectionality in conjunction, it becomes evident how our "rights to choose what we do with our bodies, our feelings, our identities, our relationships, our genders, our eroticisms and our representations" (PLUMMER, 1995, p.17) are deeply shaped by the interplays of intersecting systems of inequality. Yet, one of us was discouraged from asking participants certain demographic information, such as race/ethnicity, religion, and sexual orientation, on the assumption that these social locations were not as pertinent for understanding the romantic and sexual experiences of adults labeled with intellectual disabilities as were questions of diagnosis and severity. [25]

Disability studies scholars have emphasized the importance of taking an intersectional lens when examining the personal and intimate experiences of people with intellectual disabilities (O'TOOLE, 2015; REMBIS, 2010). Our research experiences point to the significance of other social locations. For instance, one of us found that one's religious background deeply shaped the understanding of a few participants, especially with regards to their preferences of partners, choice to remain celibate before marriage, and preferred networks for meeting potential partners. In a similar manner, applying the label "vulnerable group" to all people with intellectual disabilities fails to recognize that not all people with intellectual disabilities are equally socially positioned and that complex intersectionalities shape their experience of vulnerability (GUSTAFSON & BRUNGER, 2014). The emphasis on bio-medical understandings of disability erases or makes invisible all the other social factors, leading again to an emphasis on research and interventions focused on biology. [26]

7. Discussion

Everyone experiences risks, everyone has the right to experience them: research participation itself is a matter of equal right (IACONO & CARLING-JENKINS, 2012). That is to say that attention to protection and participants' agency are not, and should not be, mutually exclusive. While our concerns about participation in research by labeled people applies to their participation in research about any aspect of their lives and experience, we have noticed that when research is focused on their intimate lives—particularly on romance, sex, and sexuality—the challenges increase exponentially. While the emphasis is typically centered on participants' right to say "no" to research participation (demonstrated for example

in a typical consent form), it is also important to recognize participants' agency and their right to say "yes" to research participation and to have their wishes be respected (IACONO, 2006; LAI et al., 2006; LENNOX et al., 2005). It means moving away from the privileging of other people in labeled people's lives and working actively to ensure their rights to participate are respected. [27]

In this article, we identify a number of challenges that we encountered in our work while doing qualitative research with people labeled with intellectual disabilities and getting our research projects approved by ethics review boards. As we indicate, other disability scholars and qualitative researchers have encountered similar challenges in their research. Arguably, many of the issues we note in our article will resonate with other qualitative researchers working in projects involving groups of people deemed "vulnerable," and speak to broader discussions about ethics, qualitative research, and control over research (VAN DEN HOONAARD & HAMILTON, 2016). To begin, our experiences speak to discussions about how biomedical approaches, often adopted by ethics review committees, can not only limit our repertoire of research methods but also who gets to participate in research and the terms of that participation (VAN DEN HOONARD, 2002). This is not limited to people labeled with intellectual disabilities. In a similar manner, a biomedical approach may mean that other people, including for example people with other disability labels as well as older adults, are excluded from research due to assumptions of disability and aging that focus on lack of "ability." [28]

Our article also points to how the infantilization of research participants, especially those deemed "vulnerable," can sometimes lead to forms of protectionism that take precedence over participants' agency, including their right to make their own decisions, share their own perspectives, and take informed risks. In other words, the label of "vulnerable" (irrespective of which group it is applied to) can—intentionally or otherwise—lead to the disempowerment of research participants (VAN DEN HOONAARD & HAMILTON, 2016). To date, for example, few studies have addressed the perspectives of people labeled as having "profound" or multiple disabilities (BOXALL & RALPH, 2010), people who are less articulate by normative (i.e., ableist) standards, experience more "moderate" or "profound" impairments, or multiple disabilities (IACONO, 2006; KULICK & RYDSTRÖM, 2015; McVILLY & DALTON, 2006). This is partly due to practices from ethics review committees that tend to be extra "cautious" about research involving this group of individuals (BOXALL & RALPH, 2010, p.175). The consequence of this is that researchers often end up getting the "usual suspects": labeled people who use traditional forms of communication (i.e., speech), who have been determined to have "milder" disabilities, who may already have research experience or identify as self-advocates. However, if only those able to verbally speak for themselves, those for whom a determination of "decisional capacity" appears to be possible (McVILLY & DALTON, 2006), get to participate in research, we will continue to have a limited understanding of the diversity and complexity of experience among labeled people. Relying on speech and limited understandings of "decisional capacity" makes it seem as though some labeled people do not have *any* contributions to make to research, or to the ongoing conversations and debates about "intellectual disability" and the lives of

people so labeled. There is a need for more investigation of the consequences of excluding certain labeled people from research and how that shapes what we know, or think we know 1. about the lives of labeled people (ibid.), 2. of what the label of "vulnerable population" does and who has the authority to define a group of people as vulnerable, and 3. alternative ways of thinking about "capacity" and processes for determining consent. [29]

In this article we illustrate some of the unintended consequences of ethical governance (ADLER & ADLER, 2002), especially how forms of gatekeeping on the part of research ethics review boards (VAN DEN HOONAARD & HAMILTON, 2016) can shape qualitative research. Our experiences point to how ethical governance can turn into institutional processes of controlling and policing research that can be detrimental to qualitative research (ibid.). As the literature has shown, it is at times debatable who is actually being protected by these processes (AMAN & HANDEN, 2006). As VAN DEN HOONAARD and HAMILTON (2016) appropriately note, "It would be a grave mistake to assume that members of research ethics committees are the sole source of these discomfiting times" (p.5). Nonetheless, ethics review committees can play a significant role in knowledge production, and if the focus of conversations about ethics is only placed on issues of vulnerability, risks, and harm, this can make researchers, especially students, shy away from doing research with "protected classes of participants" and about "controversial topics" (p.14). [30]

As appropriately noted by ROTH (2005), "human research ethics has to evolve to respond to the continuously emerging possibilities for acting on the part of researchers and research participants" (§3). There are undoubtedly many ways to improve how research ethics committees function and approach research projects involving people with intellectual disabilities (AMAN & HANDEN, 2006). This could include evaluation by investigators of ethics committees' performance (AMAN & HANDEN, 2006). As we understand that research ethics committee membership often rotates, it is important for the knowledge to be recorded and passed on to new members, that training opportunities regarding different research approaches be provided, and that the time required for this learning be provided to board members by the university. Importantly, ethics review committees need to be educated on disablism as a way of moving beyond individualizing and pathologizing medical models of disability that can deny the agency of people with intellectual disabilities, and that promote a view of people with disabilities as only their diagnosis, and thus, not able. [31]

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